DATE 250/2013 HB 505

Mr. Chairman and House Judiciary Committee members,

My name is Karen Nelson. I am a retired hospice nurse from Helena. I am speaking as a proponent of physician aid in dying. I oppose house House bill 505.

I have spent over thirty years in the medical profession. I am proud of the tremendous improvements in pain management, comfort care and spiritual support that the hospice team is able to provide for patients and their families as they journey through the dying process. In my own practice, a good 95% of deaths are what we call as hospice workers "a good death" wherein the patient and family are physically, psychologically and spiritually prepared to let go.

Despite all of our palliative medicine tools, there are some that die with unrelenting pain and suffering. During my entire career, there only are a handful of patients whose deaths still haunt me today. I stand before you and testify in their honor.

It is important for you to know that patients do take their deaths into their own hands. The results are often tragic for the patient, the families, the physicians and the hospice workers collectively. Plans are usually secretive due to the fear of unwanted intervention.

I would like to share one heartbreaking story that illustrates this point. A highly respected scientist was diagnosed with A.L.S., or Lou Gehrig's disease, a neurologic disease characterized by progressive muscular weakness, resulting in the inability to expand the lungs to breathe in the end stages.

As his disease progressed, this man requested aid in dying from his neurologist and was denied. He then presented his case before the Kaiser Permanente Hospital Ethics Board and again was denied. After numerous lengthy discussions with his wife and three adult children regarding his wishes, only his wife was supportive. All three children were opposed, one son vehemently so. Over time, he devised a plan to end his own life which he did not share with his hospice nurse, or any of the other hospice team members.

A few months later he called his family to his side on the chosen day. After witnessing his progressive decline, his children reluctantly acquiesced to his request for support. His hospice nurse had just begun her vacation, unaware of her patient's plan. The family gathered at their home and had a celebration of his life. Then, he took an overdose of sleeping pills, antiemetics to prevent nausea and vomiting, then dropped a straw into a pint-bottle of sweetly flavored liquid morphine concentrate. He went to bed and slipped into a deep coma that lasted two full days as the family watched in horror. They had expected him to die within a few short hours. The family could not call the doctor, the emergency room, or the hospital for fear of prosecution. On the morning of the second day they were able to reach the hospice nurse at home. Out of compassion she went to their home to support the terrified family. She was also fearful of legal retribution and the potential loss of her license for providing aid, yet she could not bear to deny their request. The day progressed into another night.

I can barely speak about how it all ended, but for the sake of this bill before you I will. The son who was so vehemently opposed to his father's wishes, laid down in the bed next to his father, kissed him and whispered in his ear how much he loved him. In front of the nurse sitting at the foot of the bed he said, "I can't believe I am actually going to do this". He cupped his father's chin in his palm of his hand and simultaneously pinched his nose closed. His father died. I was the nurse that made the bereavement visit for the wife after the funeral. It was one of the hardest nursing visits of my career.

The nurse relayed this story to our hospice director in order to receive needed emotional support. She was reprimanded, but did not lose her license. Our entire hospice office needed professional counseling to process and come to terms with this death.

There are very few disease processes in which suffering cannot be alleviated. Aid in dying is a compassionate choice for those who need it. Not all of us have the fortitude to endure death with dignity. We Montanans pride ourselves on individual choice and reject government intrusion into our personal, intimate decisions, especially when facing terminal illness and death. Please keep physician aid in dying legal in Montana by voting no on House Bill 505.

I will remain available to answer any questions. Thank you for your consideration.